

PKU ORGANIZATION OF ILLINOIS
P.O. BOX 102
Palatine, Illinois 60078-0102

PKU Press

SUMMER '08

A Periodic Newsletter Published By The PKU Organization Of Illinois

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NPKUA

The nation organization has hit the ground running with lots of wonderful ventures and events underway.

Membership:

As of right now only state or regional organizations can be active members in the National PKU Alliance. The following state organizations are currently member of the NPKUA; Illinois, Indiana, Maryland, Texas, Minnesota, California, Florida, The New England connection which includes MA, RI, VT, NH, ME, CT and MACPAD (The Mid-Atlantic Connection for PKU and Allied Disorders) which includes PA, DE, MD, OH, NJ, NY, CT. Michigan and Iowa have submitted their applications for NPKUA and local organizations in Florida, Utah, and Wyoming have recently received their 501(c)(3) status and have expressed they will be submitting membership applications to the NPKUA soon. Individuals and Clinics who wish to join NPKUA can do so soon, membership program push will within the next month. Membership applications will be available online, and made available through participating clinics and the PKU News. Check the www.NPKUA.org website for undated information. "Grand Power" is a website where grandparents of children with PKU can get involved. The website already has 50 members and welcome more grandparents to join at <http://www.grandpowernpkua.org/>

National Meeting Scheduled:

"High Hopes" is the first ever national PKU conference that will be at the Embassy Suites South Hotel in Dallas, on January 15-17, 2010. The conference will have speakers as well as entertainment. More information will be posted in the press as the conference takes shape.

National Interest:

The national organization is in the works of putting together a public service announcement to attract the estimated 5,000 individuals with PKU currently not being seen at clinic or on diet, and encourage them to visit a clinic and return to diet. The PSA will be aired mid may hoping to reach all 50 states. Research is underway evaluating which states provide food and formula coverage. Efforts are being made to help all PKU patients, at every age. Research continues on national and state coverage for medical foods and formula, and for newborn screening. Summaries have been compiled on all 50 states, with additional research into coverage in Texas, Virginia, Wyoming, Kansas, D.C., Georgia and Oregon. The Advocacy Committee has determined that TX has comparatively good fomula coverage, but lacks medical food coverage. D.C., Virginia, and Georgia have little or no food or formula provisions. Wyoming, Kansas and Oregon have pending legislation.

New Director Hired:

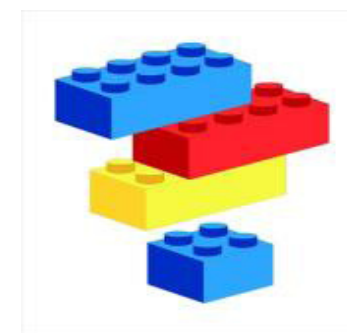
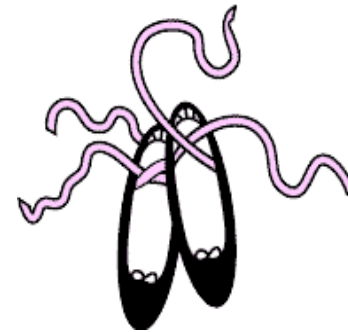
Christine Brown was recently hired as the Director for NPKUA. She has spent her entire career building and leading non-profit organizations in the areas of health care, human rights, domestic violence and Chambers of merce. She has extensive experience in coalition building, fundraising, advocacy, event organization, management and strategic planning. She "... feel(s) honored that I will now be able to use my skills, knowledge and enthusiasm to help develop and grow the National PKU Alliance as we look at literally changing the history of PKU as we know it." Christine lives in northern Wisconsin in a small town of 3,700 called Tomahawk. She is married to a professional chef, Kevin, (which comes in handy with PKU cooking) and has three boys – Keagan 6, Connor 3 and Kellen 1. Both Connor and Kellen have PKU.

Who's Who in PKU Illinois

Summer 2009 Profile

Talli is a thrilled-seeking social butterfly. She will turn 8 years old in October and she is just finishing up the 1st grade. She is mainstreamed in our local elementary school with resource support, speech and OT. She participates in jazz and ballet and Daisy Scouts. She LOVES to build with Legos, take things apart, play with her friends, and visit Disney World. Her favorite rides are the Tower of Terror, Splash Mountain, Space Mountain and Journey to Atlantis at Sea World.

She was diagnosed with Propionic Acidemia from newborn screening, although she was well into her first crisis situation when we received the results of her testing. She spent nearly a month at CHoP to stabilize her and get her diet just right. She has had over 20 hospitalizations because of illness. For the past 3 years, she has had received IV immunoglobulins every four weeks. She is unable to have the infusion run quickly, so she always has an overnight stay in the hospital. We attempted to have her use a port-a-cath, but after a year of no problems she had two episodes of sepsis, the last one being fungal and bacterial. She has other health challenges that have made it difficult to keep her stable all of the time and also just adds to her complexity. She has Long QT Syndrome, hypothyroidism, allergies, asthma, esophagitis, GERD, secondary immunodeficiency, and occasionally, she has neutropenia, low platelets, and anemia. She has a history of sleep apnea, is on her 4th set of ear tubes, has had her tonsils removed once and her adenoids twice.





28th Annual PKU Organization of Illinois Family Weekend September 25 - 27 2009

LOCATION East Bay Camp, Lake Bloomington in Hudson, Illinois. The organized event begins at 10:00 am Saturday and ends late morning on Sunday. You may come early Friday after 6:00 pm if you wish to begin your weekend early.

COST The PKU Organization of Illinois is underwriting most of the cost of this event. This year the cost is: Adult \$15, Child \$5. Anyone with PKU can attend at no charge. Payment is due at time of registration. For those wishing to help further offset the cost of the camp, any additional donations would be appreciated.

ACTIVITIES Come enjoy crafts, games, swimming, hiking, good fellowship, evening campfire, fun for all ages, and planned PKU meals beginning at noon on Saturday.

MAKE YOUR RESERVATION Detach and Mail completed **registration form** and **check** (payable to PKU Organization of Illinois) by **September 14, 2009** to **Christina Davis 2853 N. Burling, Chicago, IL 60657**. Space is limited for cabins and they will be assigned in the order that reservations are received. You may also come just for the daytime activities if you wish. Please indicate as such on the reservation form for our food preparation purposes. Additional information will be mailed to you after reservation is received.

HOTEL Anyone not wanting to "rough" it sleeping at the campsite may stay at a hotel in Normal, IL. Motel expenses and reservations are at the camper's own expense. Call us for hotel recommendations if you are unsure of where to stay.

QUESTIONS? Contact Michele Kowalski at (773) 745-4541.

----- Detach and mail the reservation form below to **Christina Davis 2853 N. Burling, Chicago, IL 60657** -----

2009 PKU Family Weekend Reservation Form

We will attend the following day(s):
 Friday - Sunday
 Saturday - Sunday
 Adults \$15, Child \$5 Saturday only

There will be _____ Adults and _____ Children in our group attending.

Total Amount Enclosed \$ _____

We will be staying in a :	Family Name, Address, Phone #
<input type="checkbox"/> Cabin	_____
<input type="checkbox"/> Tent	_____
<input type="checkbox"/> Camper	_____
<input type="checkbox"/> Hotel (cost is at your own expense)	_____

Listed below are the names of campers and ages of children whom will be attending. Indicate PKU with an (*).

	SHOP & SHARE IDENTIFICATION SLIP		AMOUNT OF PURCHASE
	0411155	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input checked="" style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>
GROUP NUMBER	STORE NUMBER	DOLLARS CENTS	
GROUP: PKU Organization of Illinois YOUR SHOP & SHARE DAYS: December 17, 18, 19, 2007			
SIGNATURE _____			
PLEASE SIGN THIS SLIP AND TURN IT IN TO YOUR CHECKER WHEN YOU SHOP. PARTICIPANTS CAN MAKE PURCHASES AT ANY JEWEL-OSCO ON THE DATE ABOVE.			
IDENTIFICATION SLIPS ARE NOT TO BE DISTRIBUTED IN FRONT OF ANY JEWEL-OSCO.			

	SHOP & SHARE IDENTIFICATION SLIP		AMOUNT OF PURCHASE
	0411155	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>	<input style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/> <input checked="" style="width: 20px;" type="text"/> <input style="width: 20px;" type="text"/>
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IDENTIFICATION SLIPS ARE NOT TO BE DISTRIBUTED IN FRONT OF ANY JEWEL-OSCO.			

Lil's Dietary Specialty Shop

Where Everyone is Special
 2738 West 111th Street
 Chicago, IL 60655

Hours	Tues-Wed, Fri 10 AM – 6 PM Thurs 10 AM – 7 PM Sat 10 AM – 3 PM CLOSED Sunday and Monday	MARCIE HARVEY President
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Phone: 773-239-0355
 FAX: 773-239-0357
 Email: lilsdietaryshop@sbcglobal.net
 Shop 24 Hours a Day At:
www.lilsdietary.com

Carrying all your favorite Low Protein Brands!
 Come on in and shop in person – where you can get low protein foods
 right off the shelf!

NETWORK PKU CONFERENCE 2009

by Barbara Goss, MS, RD, LDN
University of Illinois @ Chicago

I had the pleasure of being invited to this meeting on April 24th-26th in Denver, Colorado. The meeting was a collaboration between Applied Nutrition Corp, Biomarin Pharmaceutical Inc., The Children's Hospital in Denver, and Johnson and Wales University (JWU).

The weekend program was filled with educational and culinary workshops to increase attendees' knowledge about PKU and Low Protein Cooking. All teenagers and adults with PKU and other interested metabolic disorders patients who follow a protein restricted diet and their families were divided into concurrent workshop groups along with some joint general sessions. These included: a talk on "Research in PKU Drug Therapy" given by Elaina Jurecki, MS, RD, nutrition specialist from Biomarin who was the keynote speaker at the 2008 annual meeting; "Healthy Choices and More Phe" given by Laurie Bernstein, MS, RD, The Children's Hospital, and "Transitioning Teens to Adult PKU Management" presented by Sandy Simons, MA, RD from Applied Nutrition.

All of the sessions were held at Johnson and Wales University which is renowned for being one of the best degree culinary institutions. The attendees were divided into different themed groups, and I was in the Miami Beach group where I met several families from across the country. One family was from Dubuque, Iowa and has attended the annual IL meeting in the past with their grandparents who brought them to Denver. These workshops were in the culinary labs and conducted by the JWU chefs who had developed the theme recipes which were submitted ahead to the Children's Hospital dietitians for phe content approval. These sessions which provided printed recipes, demonstrations, and tasting samples included: Cold Soups and Summer Delights, Super Summer Salads, Spicing up your Barb-B-Que (given by Malathy Ramanujam, Taste Connections, who also has spoken and demonstrated at a previous annual meeting and given a cooking class at UIC), Summer Desserts, and a hands on DNA Extraction we did with a discussion on "Do You Know Your Genes from your DNA?" given by genetic counselors from Children's Hospital. I have several recipes to share- two that I have that I since tried at home: one from Malathy's barbeque demo (Best Un "Beetable" Burgers which has only 25 mg phe,) and a Brussels Sprout Slaw recipe (36 mg phe). I am going to share both with you, and want to stress that if you don't like beets or brussel sprouts, you won't really taste them in the recipe. They do require a food processor, but as parents when you are preparing recipes, it helps to make several items in a food processor at the same time before packing it all away, since this is more time efficient with our busy life style. I also have a good nutritious recipe, Roasted Sweet Potato and Apple Soup, to share with you that has 30 mg phe per serving. If anyone would like any of the other recipes, please contact me at 312-996-9283.

The return of the Iron Chef America-PKU Low Protein Cooking Challenge was a big success. The secret ingredient was an Apple that had to be used in 3 recipes- appetizer, entrée, and dessert. Each group of 2 sections had one hour to create a recipe from a list of ingredients that were available, write up the recipe, and calculate the phe content per serving, and present it to the chefs for judging. The dietitians were there as supervisor/assistants but not as the "hands-on" creative patients. Family members were not allowed to be in the Iron Chef competition. They were in the session presented by Sandy Simons. There was also an excellent presentation from the director of nutrition from Applied Nutrition, Bridget Wardley, MS, RD, who discussed the nutrition essentials in the PKU diet along with the opportunity to taste test several of the Applied Nutrition products along with various flavorings.

Pam Kowalczyk, daughter of Linda and Jim, one of our own CMH patients from Illinois was there with her boyfriend. She has graduated from college and is currently an elementary teacher in Dubuque, Iowa. She presented the recipes for her group to the judges, and they won the overall Iron Chef competition for 2 out of the 3 categories. Michelle is pictured here with her presentation to the audience.

This was a great event for meeting other families and learning about making low protein foods both palatable and nutritious. This culinary program is usually offered every few years, and would be highly recommended as a "Top Chef" Educational program.

NEW

Maddy's ONLINE shop

@www.dietforlife.com

*Cinnamon Chip
Muffin Mix*



*Banana
Muffin Mix*



Homestyle™ Bakery Mixes

From


APPLIED NUTRITION corp™
METABOLIC NUTRITION SUPPORT

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Network PKU Conference An Interactive Low Protein Culinary Experience

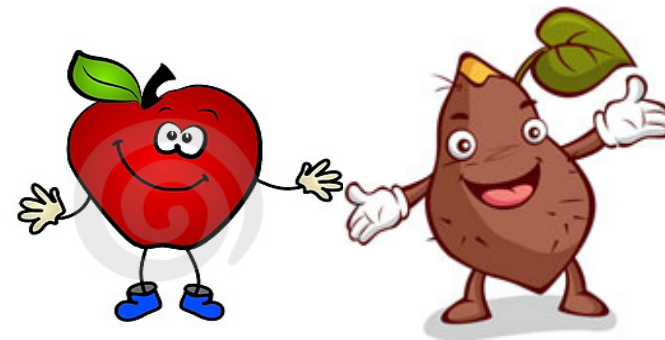
Recipes from the Event

Roasted Sweet Potato and Apple Soup

Yield: 8 servings Serving Size: 5oz Protein: 0.72g PHE: 30.1mg

INGREDIENTS:

1 ½ cup Sweet Potatoes cubed
1 cup Red Apple, peeled, cored and sliced
1 cup Onion, chopped
3 cloves Garlic
2 tablespoons Olive Oil
4 cups Water
To taste Salt and Pepper



METHOD OF PREPARATION

Preheat Oven to 450 degrees F. Place sweet potatoes, apple, onion and garlic in roasting pan and toss them with oil. Roast uncovered until soft. Transfer roasted vegetables to blender or food processor and pour in enough water to cover them. Add pinch of salt and pepper, then puree. Thin as needed with water. Return to heat to warm and serve.

Brussels Sprout Slaw

Yield: 8 servings Serving Size: ½ cup Protein: 1.11g PHE: 35.6mg

INGREDIENTS:

1 cup Brussels Sprouts, shredded
1 cup Red Cabbage, shredded
1 cup Carrots, Grated
1 cup Dates, chopped

METHOD OF PREPARATION

Combine all ingredients, season with salt and pepper, marinate for 2 hours.



PKU Organization of IL – 2009 Calendar of Events

<u>DATE</u>	<u>EVENT</u>	<u>LOCATION</u>	<u>TIME</u>	<u>HOST/CONTACT</u>
June 1 st	Andrew Craig Scholarship	PKU Org. of IL Website	Beginning	www.pkuil.org
July 25 th	Propionic Acidemia Foundation Family Day			Jill Franks, 877-720-2192 paf@pafoundation.com
TBA	Cooking School Summer	TBA		Eva Brandon (708-285-5006)
August TBD th	Handicapped Children's Fund golf outing	Contact Tom for location and time	TBD	Tom Gallager (708) 424-7351
August 31 st	Andrew Craig Scholarship	PKU Org. of IL Website	DEADLINE	www.pkuil.org
September 19 th	BIG WIG Golf Outing/ Silent Auction		TBD	Lisa & Steve Bennett (847) 359-0506
September	PKU Family Camp	Lake Bloomington in Hudson		Michele Kowalski (773) 745-4541 Bruce Kimbrell (309) 827-4706
October TBD	Carlos Galvez Memorial Golf Tournament	Broken Arrow Golf Club Lockport, Illinois	TBD	Carla & Del Halter cghalter11@aol.com
November 7 th	Annual Meeting	Medinah Country Club	9 am – 4:30 pm	www.pkuil.org or voicemail
Summer/Fall	Jewel Shop-N-Share	Coupons in Summer Press and Annual Meeting Folders		Mike McMahon (630) 416-3170

For more information of these events call our voicemail at (630) 415-2219 or via e-mail at info@pkuil.org
Watch for updates in the PKU Press and check out our web site <http://www.pkuil.org>

As events are scheduled the calendar will be updated and put on the website.

The **PKU PRESS** is published three times a year as a service of the PKU Organization of Illinois. In conjunction with the three Illinois clinics, we are working together to provide information, offer support, highlight achievements, and provide services for the benefit of the PKU community.

We welcome your input and ideas. Requests for additional copies or correspondence should be addressed to:

PKU PRESS Editor
P.O. Box 102, Palatine, IL 60078-0102
Email: www.pkuil.org

2009 PKU Organization of Illinois Officers

Joe Annunzio - President
Julie Kelly - Vice-President
Frank Salemi - Treasurer
Christina Davis - Secretary

2009 PKU Organization of Illinois Board Members

Lisa and Steve Bennett, Larissa and Frank Bruno, Jill Franks, Mike McMahon, Eva and Michelle Brandon, Jim Critchfield, Heather and David Ricca

2009 PKU Organization of Illinois Honorary Members

Barbara Goss and Hazel Vespa



PKU ORGANIZATION OF ILLINOIS
SERVING THE NEEDS OF PKU AND ALLIED DISORDER FAMILIES

PKU and Allied Disorder Families!

Register with the PKU Organization of Illinois! Registering will add your information to our mailing list and family directory and ensure you receive notifications of all our events and updates and the Press. You can also register online at www.pkuil.org

Please help us by filling out the form below and mailing it to address at bottom.

----- Detach and mail to the address below -----

Last Name : _____
 First Name(s) of Parents/Guardians or Self: _____
 Address : _____
 County: _____
 Phone: _____
 Email: _____

** (Providing an email address will help the Organization keep in better touch with families)**

Clinic: _____
 PKU or Allied Disorder: _____

List all the children in your household and their birthdates. Please mark children with PKU or Allied Disorder with an asterisk (*):

Please mail forms to: Christina Davis, 2853 N. Burling #2N, Chicago, IL 60657

WEBSITE WWW.PKUIL.ORG
 P.O BOX 102 PALATINE, ILLINOIS 60078-0102
 PHONE 630-415-2219
 AFFILIATED WITH CHILDREN'S MEMORIAL HOSPITAL UNIVERSITY OF ILLINOIS HOSPITAL RUSH UNIVERSITY MEDICAL CENTER
 A NOT-FOR-PROFIT ORGANIZATION FEDERAL I.D. #36-3320115

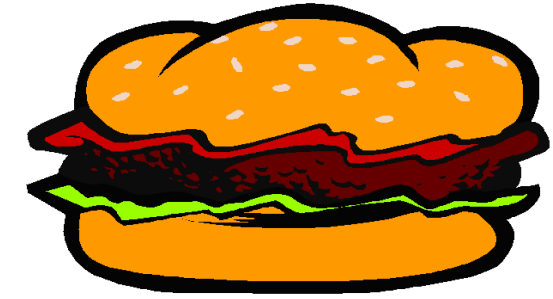
Best Un "Beetable" Burgers

Yield: 4-6 servings Serving Size: 1 burger

If recipe makes 4 burgers	Protein: 0.85g	PHE: 24.8mg
If recipe makes 5 burgers	Protein 0.70g	PHE: 19.8mg
If recipe makes 6 burgers	Protein 0.56g	PHE: 16.5 mg

INGREDIENTS:

- 2 tablespoon Raw Beets, grated finely
- ½ small Zucchini, grated
- ½ small Carrot, peeled and grated
- 1 medium Granny Smith apple, peeled and grated
- ¼ medium Red onion, minced
- 1 teaspoon Fresh Garlic, minced
- 1 tablespoon Tomato ketchup
- 2 tablespoons BBQ Sauce
- ¼ teaspoon Liquid Smoke
- 3 tablespoons Canola Oil
- ½ cup Low protein bread crumbs (made from 2 slices of dried low-protein bread)
- ¼ cup Taste Connections Multi Baking Mix
- To taste Salt and Pepper



METHOD OF PREPARATION

Squeeze out excess moisture from grated vegetables. In food processor or big bowl blend onions, garlic, ketchup, bbq sauce, salt, pepper and canola oil until smooth. Add to grated mixture. Add bread crumbs and TC-Multi Baking Mix to bowl with vegetables. Mix thoroughly until everything is blended well. Refrigerate for one hour. With wet hands, shape into 4-6 burgers. Cook 3 minutes on each side on grill lightly brushed with oil.



2009 Spring Cooking Class Welcoming Back Chef Jeff Masse!

The 2009 Spring Cooking Class, sponsored by BioMarin Patty/Sibley and hosted by Eva Brandon and Michelle Brandon – was another huge success! Jeff Masse, owner of the Cooking Store, returned to provide a great hands-on experience for all.

Held at the Renaissance Hotel in Oak Brook, approximately 40 people were in attendance and we raffled off many cooking items to complete our day of low protein cooking for PKU and Allied Disorders.

Families were able to create and taste test the following low protein dishes from the “Apples to Zucchini” Cookbook and family favorite recipes from the Brandon’s –

Country Time Blueberry Pancakes
 Watermelon Gazpacho
 Lazy Cooks Guacamole with Low Protein Tortilla Chips
 Italian Bread Salad
 Picnic Season Potato Salad
 Strawberry Fool
 Party Fudge Bars

PKU Awareness Month Recap

Thanks to all PKU and Allied Disorders families who came out to walk and support PKU Awareness Month

The PKU Organization of Illinois celebrated PKU Awareness Month with our 3rd annual walk a thon – held Sat. May 16, 09 at the Neuqua Valley High School in Naperville, Illinois. Families came out to walk, eat and have some fun while raising funds for the PKU Organization of Illinois.

Turn out exceeded last year – with the windy weather not stopping families from coming out and participating.

Thank you to VitaFlo, BioMarin, Allied Nutrician, Cambrooke and Patient Power for your sponsorship and support and a huge thank you to the Brandon family and David and Heather Ricca for organizing and launching this year’s event.

And finally a big thank you to all the PKU and Allied Disorder families who donated and came out to support this big event!

Annual Appeal Letter

To our PKU Parents, Families, PKU Press Subscribers, and Friends,

I am writing to ask for your donation to our Annual Fundraising Drive.

The PKU Organization of Illinois NEEDS YOUR FINANCIAL SUPPORT! We’ve been successful in fundraising efforts these past two years and shortly we’ll have the ability to keep expanding our support to the community and consider significant donations to research. Please help us continue to attain these goals and continue to expand our capabilities to aid the community. Support from you has even more importance because it indicates your desire for us to accomplish the goals of our Organization.

Just think of what we’re all getting for our donation:

- Our parent directory which is updated and distributed every two years.
- No subscription fees for the PKU Press, 3 times per year.
- Continuous/on-going educational events for us to attend so we’re up to date with successful diet management ideas.
- Social events to get parents and kids together to share ideas (new parent meetings, cooking classes and more for 2009!).
- Educational grants for our PKU students. **We increased the scholarship amount available from \$2,000 to \$4,000 in 2005 and increased the number of scholarships we award in 2007.**
- Active involvement by your board members at the State and National levels with legislation and new developments in PKU treatment.
- Our 24-hour voice mail (630) 415-2219 as well as our web site { **HYPERLINK "http://www.pkuil.org"** }.
- In 2005, we **expanded Organization** to now include those individuals and families with Allied Disorders.
- Our Annual Meeting, which has **attracted national attention** for the quality of the presentations on PKU research and treatment and soon we’ll be in a position to significantly aid those needing research funds.

Speaking of our Annual Meeting, we have begun planning another great meeting for this year. BUT, this meeting continues to be our single largest annual expense. With your help, we can continue to provide the financial means necessary to continue to have heavy hitting Annual Meetings with speakers that benefit all of us.

With your gift, we’ll make us add programs in the future that meet your needs and requirements. Whether you contribute \$25, \$50, \$75, or more you’ll know you’re making a difference in PKU for you, our kids, and the members of your family. **PLEASE SAY YES** in the box below, and pledge your financial support.

YOUR CONTRIBUTIONS ARE FULLY TAX DEDUCTIBLE***
REMEMBER, YOUR PKU ORGANIZATION IS AN ALL-VOLUNTEER PARENT ORGANIZATION. 100% OF ALL DOLLARS RECEIVED GO TO PROVIDE PROGRAMS AND SERVICES FOR PKU CHILDREN AND THEIR FAMILIES.

Many Thanks for helping to keep our Organization strong,

Joe Annunzio, President
 President

 Cut along line and return the bottom portion with your contribution

REMEMBER OUR CHILDREN AND THE FUTURE OF PKU

[] **YES**, I want to help continue the programs provided by the PKU Organization of Illinois. Enclosed is my contribution in the amount indicated below.*

[] \$25 [] \$50 [] \$75 [] _____ Other

 (Your Name)

 (Address)

 (City)

 (State)

 (Zip)

*Note: Your employer may match your gift. Contact the Personnel or Community Relations Department of your company for details.

***Thank you for your generosity. All contributions are tax deductible as allowed by law. Please make checks payable to the “PKU Organization of Illinois”; P.O. Box 102, Palatine, IL 60078-0102. **We will acknowledge your donation.**

COMMUNITY CORNER

What's Going on in our PKU Community This Quarter

SAVE THE DATES

ANNUAL MEETING

The Date is Set! 2008 Annual Meeting

November 7th, 2009

Medinah Country Club

We're planning now so you have ideas send em in!

info@pkuil.org

MSUD National Meeting

The Date is Set!

June 24-27 2010

Questions? Email – attn. Barb Mudrick:

info@pkuil.org

Also – look for an MSUD feature in our next newsletter!

PKU Northwestern Alliance 6th Annual

Family Camp

September 4th -7th 2009

The PKU Northwest Alliance invites individuals with PKU and other low-protein diets, plus their families and friends, for a long weekend of fun at the Washington Family Ranch in Central Oregon.

All ages are welcome. For more information or to register – visit the follow sites:

<http://www.swiftpage2.com/CampResource/2U0SHTQHHQU0LR7W/2/text.pdf>

<http://washingtonfamilyranch.younglife.org>

Patient Power Webcasts

Patient Power has had a huge success with the launching of their Webcast series – designed to help patients and families utilize the best care and resources available. Upcoming programs are

July 7th and August 13th.

For more information visit – or the PKU Organization of IL Website

<http://www.patientpower.info/pku/spring2009.asp>

2009 BIG WIG/PKU Registration Form

Due By September 5, 2009

Name: _____

Address: _____

E-Mail (IMPORTANT!): _____ **Phone #:** _____

*Preferred Foursome: _____

*If you have a foursome you would like to play with, let us know who they are. If not, an extremely talented trio will be assigned to you. Remember, this all goes to charity! (PLEASE NOTE: IF SIGNING UP A FOURSOME WITH ONE REGISTRATION FORM, A CHECK OR CHECKS FOR EACH PERSON MUST ACCOMPANY THE REGISTRATION FORM.)

Cost Per Person

\$125.00

*If signing up more than one person on a registration form, please include addresses and e-mails for each participant.

Send your forms and check made payable to **Women In Golf, Inc.** to:

Women In Golf, Inc.

c/o Lori Knaub

1026 Bentley Lane

Bartlett, IL 60103

PKU Organization of Illinois

c/o Steven Bennett

4030 New Britton

Hoffman Estates, IL 60192

OR

We will be contacting you **by e-mail** (if possible) with further information seven days prior to the event. Please contact us at: **Bennett19@earthlink.net**

OR

CALL: LORI KNAUB: 630-837-0981 / STEVE BENNETT : 847-359-0506

IF YOU HAVE ANY QUESTIONS

REMEMBER TO CHECK OUT OUR WEB SITE

<http://WWW.PKUIL.ORG>

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2009 BIG WIG PKU Golf Outing

Sponsored By
Women In Golf
PKU of Illinois

Date: September 19, 2009

Check-In begins 12:00 pm

Register Your Foursome By
September 5th !!

Where:

Tamarack Golf Club
24032 Royal Worlington Dr
Naperville, IL 60564

www.Tamarackgc.com

Registration Fees:
\$125.00 - per Golfer

**The proceeds will
go towards research
and the PKU
Organization of IL !!**

For more info or to register call:

Steven & Lisa Bennett 847.359.0506
Lori Knaub 630.837.0981

Email:
Bennett19@earthlink.net
Subject line: PKU Golf Outing

Outing Highlights

- **Pre-Round Lunch - 12:00 pm!**
- **Shotgun Start - 1:30 pm !**
- **Appetizers with 1 Hr. open bar**
- **Dinner**
- **Cash bar during and after dinner**
- **Silent and Live Auctions**
- **Raffle Prizes**
- **AND MUCH MORE !!**



COMMUNITY CORNER

What's Going on in our PKU Community This Quarter

WELCOME LAUREN KIME TO UIC!!

Hi, I'm Lauren Kime. I'm so pleased to have become a part of the metabolic team at UIC! As a registered dietitian, I am eager to be working families and patients in metabolics. Before coming to UIC, I worked as clinical dietitian for Sodexo. While attending UW-Madison, I was a counselor at maternal PKU camp for 2 years. I enjoyed this time getting to know the girls, cooking and just having fun. It helped give me a deeper understanding of PKU from a more personal perspective. I look forward to my involvement and getting to know the members and families of this organization!



FROM THE BOARD ROOM

Remaining Board Meeting Dates:

July 9th - conference call
August 20th
October 8th

Anyone is welcome to attend – for more information or minutes or agendas – please contact Christina Davis at 312-968-7247.

There will be open seats on our board for the 2010 year – if you are interested in joining please send an email to info@pkuil.org.

RELEASE OF MEDICAL INFORMATION:

Patient: Complete the upper portion of this form, and forward to your physician who will in turn complete the lower portion. Your physician should then forward this form to the PKU Organization of Illinois. (You may wish to assist your physician by including a pre-addressed envelope).

I, _____, do hereby request and authorize
 (Name of Patient)
 _____ to release medical information indicating the
 (Physician's Name/Institution)
 Diagnosis of PKU / Allied Disorder concerning _____
 (Name of Patient)
 to the PKU Organization of Illinois Andrew Craig Memorial Scholarship Program.
 (Patient Signature) _____
 (Guardian Signature) _____
 (Required if Patient if a Minor)

I, _____ do hereby attest that _____
 (Physician's Name/Institution) (Patient Name)
 has been diagnosed with PKU or an Allied Disorder.

 (Physician/Institution)

 (Address)

 (Physician Signature)

 (Date)

PERSONAL ESSAY:

Include a short essay describing yourself, your experiences with PKU/Allied Disorder, and your future aspirations.

ADDITIONAL INFORMATION:

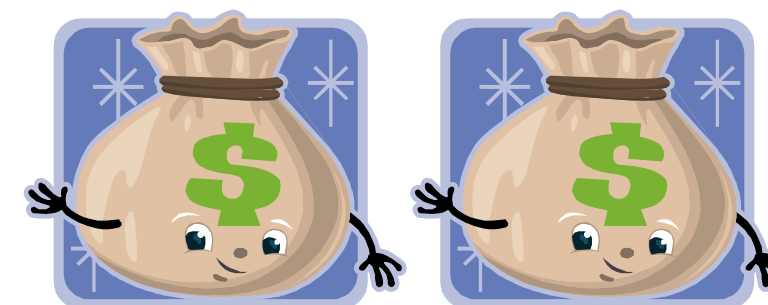
1. Proof of enrollment (i.e. copy of class schedule)
2. Proof of residence (i.e. copy of Drivers License or school ID)



The Andrew Craig Memorial Scholarship Fund is looking to help qualified and deserving students enrolling in College / University / Vocational Institutions in the Fall of 2008!

Applications are available between June 1st and August 31st, 2009 on the www.pkui.org website, and must be mailed and postmarked by August 31st, 2009.

We want to hear about you, you're experiences with PKU, and your future aspirations. This year, five \$2,000 Scholarships will be awarded at the PKU Organization of Illinois Annual Meeting on November 7th, 2009.



Andrew Craig Memorial Scholarship Guidelines & Procedures

For the eleventh consecutive year, the PKU Organization of Illinois has elected to award dollars for education to qualifying individuals with PKU or Allied Disorders. This year, \$2,000 scholarships will be awarded to five individuals with PKU or an Allied Disorder, who reside in Illinois, and who are enrolled in an accredited college, university, or vocational school in the fall of 2009. A student may win more than once, but not in consecutive years.

Guidelines:

The applicant must submit a complete application and,

- Show proof that he/she will be enrolled in classes during the school year for which the scholarship is being awarded
- Have been diagnosed with PKU or an Allied Disorder
- Show proof of primary residence in Illinois
- Submit a short essay
- Will apply scholarship funds to College/University/Vocational school expenses (i.e. course fees, textbooks, room & board)

Procedures:

- An application should be obtained via our website ({ HYPERLINK "http://www.pkuil.org" }) OR by writing to us at : PKU Organization of Illinois
Attn: Andrew Craig Memorial Scholarship
P.O. Box 102
Palatine, IL 60078-0102
- The application will be available from June 1st to August 31st.
- **The application must be completed and mailed/postmarked by August 31st.**
- The application will be reviewed by the Board of Directors, and ALL applications meeting the required criteria will be presented to the Board of Directors for consideration and selection.
- The winners of the scholarships will be notified by mail, and invited to attend the PKU Organization of Illinois Annual Meeting to be recognized by the Board of Directors and the PKU/Allied Disorder Community at large.

PKU Organization of Illinois 2009 Andrew Craig Memorial Scholarship Application

Please complete ALL information requested (Print clearly or Type)

Completed form is to be mailed by August 31st to:

PKU Organization of Illinois
Attn: Andrew Craig Memorial Scholarship
P.O. Box 102
Palatine, IL 60078-0102

APPLICANT DATA:

Name: _____
First
Middle
Last

Birth Date: _____

Permanent Mailing Address: Street: _____
City: _____
State: _____
Zip: _____

Contact Telephone Number: (_____) _____
(Area Code)

Email Address: _____

The undersigned hereby acknowledges that the prescribed criteria for eligibility for award of scholarship funds of the PKU Organization of Illinois have been met, and that the information provided within this application is correct.

Applicant Signature: _____

COLLEGE/UNIVERSITY/VOCATIONAL INSTITUTION DATA:

Name of Institution: _____

Address of Institution: _____
(City)
(State)
(Zip)

Month and Year of first semester attended: _____